

Public Spending for Disability in the United States: 1997-2006

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Spending by federal, state, and local units of government constitutes a large proportion of the resources available to assist people with disabilities in the United States. These funds pay for health care, income maintenance, special education, vocational rehabilitation and training, and long-term care including housing and related residential support services. Funds are allocated directly to individuals as well as to schools, health care organizations, and tens of thousands of nonprofit and proprietary disability services organizations.

This paper describes an ongoing study of trends in public-sector disability spending and services from 1997 to 2006. The study was funded in part by the federal government's National Institute on Disability and Rehabilitation Research. The principal purpose of the study is to identify trends in federal, state, and local governmental spending for services for persons with intellectual and developmental disabilities (I/DD), mental illness, and physical disabilities. In addition to presenting a brief statistical summary of annual spending and services trends, this paper provides additional information on long-term care, the most extensively funded disability service in the United States. The need for long-term care services will continue to grow rapidly as the number of older Americans rises.

The findings of this study illustrate the increasing size and growth rate of the disability market as well as a strong, continuing shift away from the use of institutional and nursing facility care toward more individualized community residential and personal support services. Long waiting lists for community-based services, however, indicate that demand far exceeds supply (Kaiser Commission on Medicaid and the Uninsured, 2009; Ng, Harrington, and Kitchener, 2010). The continuing shift in public-private funding toward community residential services and supports, as well as the emerging use of residential support technologies, will help meet the growing demand in future years. The community development finance field can play a particularly important role in helping to significantly expand the provision of affordable community-based housing and related supports for people with disabilities.

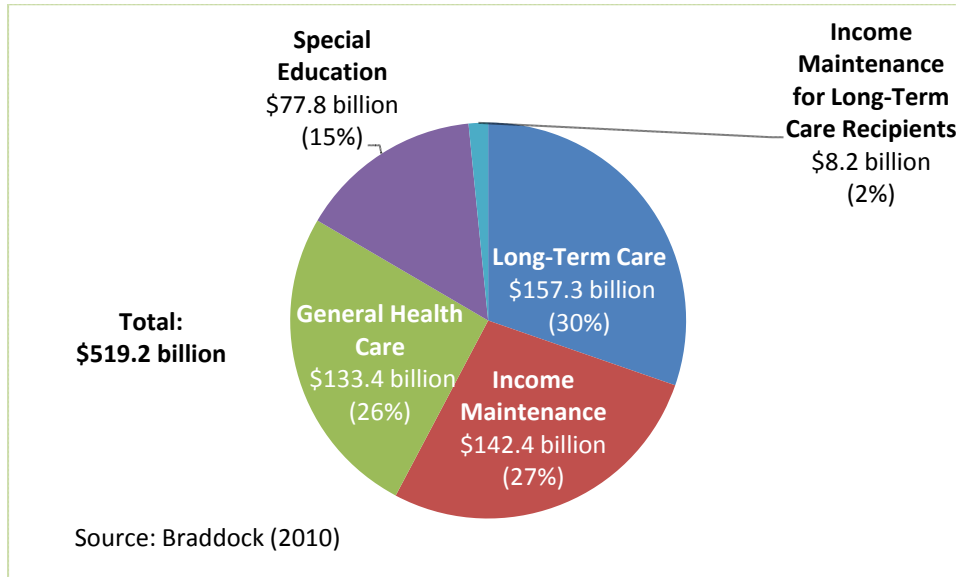
Overview of Public Spending and Services for Disability

Public spending for disability programs in the United States totaled \$519.2 billion in fiscal year 2006 (see Figure 1) (Braddock, 2010). This constituted 11 percent of total federal, state, and local spending in the U.S. that year. Thirty percent of disability spending (\$157.3 billion) was allocated for long-term care; 27 percent for income maintenance (29 percent when long-term care-related income maintenance support is included); 26 percent (\$133.4 billion) for health care; and 15 percent (\$77.8 billion) for special education. The \$8.2 billion for long-term care-related income maintenance includes federal Supplemental Security Income (SSI) benefits for Home and Community Based Services (HCBS) Waiver participants with disabilities (\$4.5 billion) and SSI State Supplement payments for community-based services (\$3.6 billion). The Medicaid HCBS Waiver program, authorized under Title XIX of the Social

Security Act, allows participating states to develop residential alternatives for individuals with I/DD who would otherwise require care in a nursing facility, state mental hospital, or state institution.

Figure 1

U.S. Public Spending for Disability in 2006



Sixty-three percent of spending for disability services and income maintenance (\$329.1 billion) in fiscal year 2006 was allocated by the federal government; 28 percent (\$142.7 billion) by state governments; and 9 percent (\$47.3 billion) by local units of government, primarily school districts. A total of 53.6 million individuals with disabilities were assisted by public sector financial commitments in 2006 (see Table 1). This is a duplicated count and includes income maintenance assistance to 21.4 million individuals; general health care assistance to 17.3 million individuals; long-term care assistance to 7.9 million individuals; and assistance to 7.0 million children and youth in special education programs.

Total disability spending advanced 35 percent in inflation-adjusted terms, from \$381.6 billion in 1997 to \$519.2 billion in 2006. Spending grew 3.5 percent per year above the rate of inflation during this decade. The most rapid annual growth was 6.7 percent from 2001 to 2002, and the slowest average annual growth was 0.6 percent from 2005 to 2006. Disability-related health care spending increased 56 percent in inflation-adjusted terms from 1997 to 2006, growing from \$85 billion to \$133 billion (see Figure 2). Spending grew 48 percent for special education, 31 percent for income maintenance, and 21 percent for long-term care services.

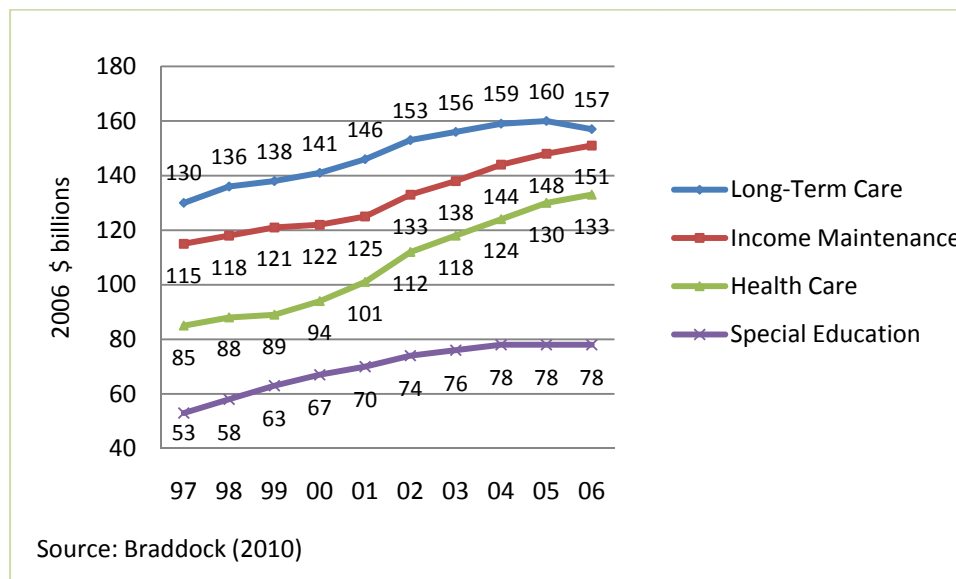
Table 1

Disability Services and Income Maintenance Recipients in 2006

Program	Recipients
Income Maintenance	21,398,280
Supplemental Security Income (SSI)	5,898,959
SSI State Supplement	2,293,430
Social Security Disability Insurance (DI)	6,356,980
Adult Disabled Child (ADC)	745,190
Veterans' Compensation	2,683,117
Food Stamps	2,616,000
Housing and Urban Development (HUD)	804,604
Health Care	17,300,620
Medicare	6,586,337
Medicaid	8,861,890
Veterans' Medical Care	1,852,393
Special Education	7,006,421
Long-Term Care (LTC)	7,929,536
Community LTC & Related Services	6,929,602
I/DD State Agency Programs	1,494,716
Mental Illness State Agency Programs	3,351,118
Medicaid HCBS Waiver: Physical Disability	207,778
Medicaid Home Health Care	725,856
Medicaid Personal Care	624,063
Related Services	
Vocational Rehabilitation (VR)	202,983
Independent Living	266,580
Veterans' Rehabilitation	55,469
HUD Construction	1,038
Institutional LTC	999,934
Nursing Facilities (all disabilities)	882,710
I/DD Institutions (public/private 16+)	68,293
Mental Illness Institutions	48,931
Total Recipients	53,634,857

Figure 2

Disability Spending in the U.S. by Activity Category, Adjusted for Inflation, 1997-2006



There was significant variation in the growth of public spending among different states from 1997 to 2006. The most rapid average annual growth rates in disability spending were in Arizona, Nevada, Alaska, New Mexico, and Idaho (between 5.3 and 6.7 percent growth). These states were also in the top 20 nationally in average annual general population growth during this period. The five states with the slowest annual growth rates in disability spending were Connecticut, Massachusetts, North Dakota, Michigan, and Illinois (between 2.1 percent and 2.6 percent growth in spending). These states ranked in the bottom third in general population growth and grew less than one percent. The general population declined between 2005 and 2006 in Michigan.

The number of participants receiving long-term care services grew rapidly from 1997 to 2006, increasing by 24 percent from 6.4 million individuals to 7.9 million individuals. This growth was primarily attributable to expansion in the number of recipients of home health care, personal care, and HCBS Waiver services. The number of disabled recipients of health care services increased even more rapidly, growing by 49 percent from 11.6 million individuals in 1997 to 17.3 million individuals in 2006. Medicaid and Medicare beneficiaries constituted 89 percent of all disabled health care beneficiaries and increased 45 percent and 43 percent, respectively, during 1997 to 2006. Income maintenance beneficiaries increased 24 percent, growing from 17.2 to 21.4 million individuals. Disability Insurance (DI) and SSI beneficiaries, constituting 58 percent of all disabled recipients, increased by 30 percent and 28 percent, respectively, during the 10-year period. Special education student enrollment jumped 19 percent, from 5.9 million to 7.0 million students. The most rapid growth in student enrollment from 1997 to 2006 was 44 percent among children and youth with developmental disabilities (intellectual disability, autism, traumatic brain injury, and developmental delay); there was growth of 15 percent among students with

physical disabilities; and 5 percent among students with emotional disturbance. The number of students with autism, a subcomponent of developmental disabilities, increased 345 percent from 1997 to 2006.

Increased spending for disability-related services is attributable to broader legislative mandates for services in special education, community residential supports, health care, and income maintenance. National Health Expenditures as a share of the GDP increased from 13.5 percent in 1998 to 15.8 percent in 2006 (Centers for Medicare and Medicaid Services, 2009). Implementation of the Americans with Disabilities Act of 1990 and the Individuals with Disabilities Education Act (IDEA) has led to increased services and supports for many children and adults with disabilities. Increasing life spans of people with disabilities has also led to growing demand for such services (Braddock, Hemp, Rizzolo, 2008). Class action litigation has promoted alternatives to the institutionalization of people with disabilities (Herr, 1983; Herr, Arons, & Wallace, 1983; Parry, 2010).

Growth of Community Long-Term Care Services and the Medicaid HCBS Waiver

In 2006, the nation budgeted 51 percent of public long-term care disability funds for community residential services, defined here as homes, apartments, and facilities that served 15 or fewer persons per setting, and related vocational, family support, and service coordination programs. Forty-nine percent of total long-term care spending was allocated for state and private institutions and nursing facilities serving 16 or more persons at each site. Twenty-four states committed less than 50 percent of their long-term care financial resources for community services activities in 2006. Only seven states—Alaska, Arizona, California, Maine, Minnesota, New Mexico, and Vermont—committed more than 65 percent of total long-term care funds to community services. However, all states significantly increased the proportion of funds allocated to community services versus state-operated institutions and nursing facility care over the decade 1997-2006.

The I/DD field is transforming from an institution- and nursing facility-dominated service delivery system to a community residential and family support system more rapidly than its counterparts in mental health and physical disability (Braddock, 1992). From 1997 to 2006, the proportion of community services long-term care funding for persons with I/DD long-term care increased from 68 percent to 78 percent. The proportion of spending committed to community mental health care versus state hospital or nursing facility care increased from 51 percent to 56 percent, and the proportion of spending for community services for persons with physical disabilities increased from only 19 percent to 25 percent.

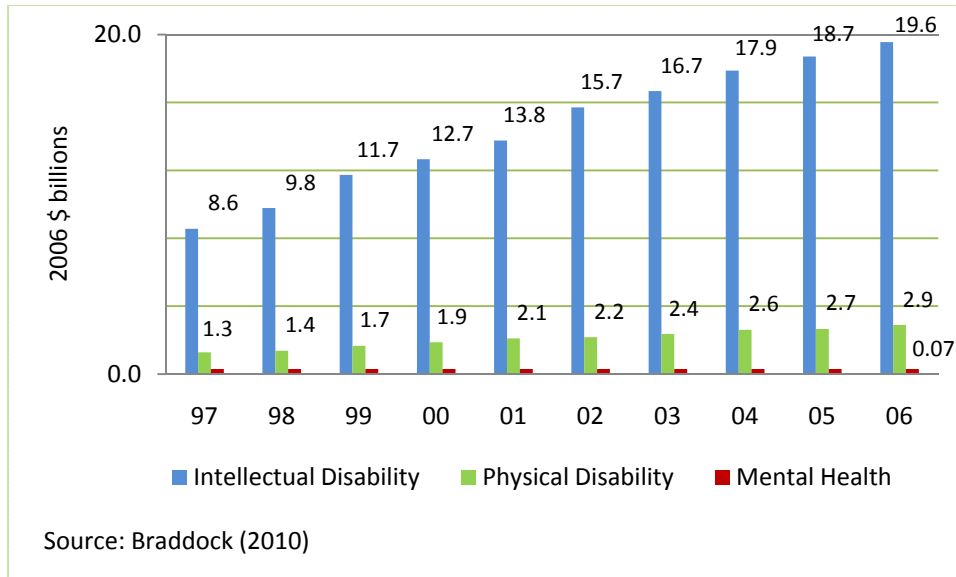
Two factors largely account for the more modest growth of community service funding for persons with physical disabilities and mental illness compared with I/DD. First, financial commitments for HCBS Waiver programs are smaller for physical disability and mental illness. Second, although there is pressure to reduce utilization of state psychiatric hospitals and avoid high per diem costs, this often leads to inappropriate placements in nursing facilities and in congregate care boarding homes (see Bazelon Center for Mental Health Law, 2009; Fisher, Geller, White, and Altaffer, 1995).

Rapidly increasing funding for community residential services in I/DD is largely attributable to the growth of the Medicaid HCBS Waiver (see Figure 3). Adjusted Waiver spending advanced 10 percent per

year for persons with I/DD from 1997 to 2006 (Braddock, 2010). The growth of HCBS Waiver spending for mental health services grew from a markedly smaller base than that for persons with I/DD, but advanced 37 percent per year during the same period.

Figure 3

Growth of Home and Community Services Waiver Spending by Disability Group, 1997-2006



Community residential services spending for persons with I/DD first surpassed consolidated I/DD spending for institutions and nursing facilities in 1989 (Braddock, Hemp, and Rizzolo, 2008). Institutional and nursing facility spending for persons with I/DD declined one percent per year during the decade 1997 to 2006. In contrast, I/DD community services spending increased five percent per year. Class action litigation and the implementation of the Americans with Disabilities Act have been major contributing factors in stimulating the growth of community services and supports, particularly for persons with mental disabilities (Braddock, Hemp, & Rizzolo, 2004).

Community mental health spending also grew five percent per year during 1997 to 2006, albeit from a much smaller base than I/DD spending. However, mental health spending for state institutions and nursing facility settings, in contrast to I/DD services in such settings (which contracted significantly), increased by three percent per year. Most of the mental health increase in spending for institutional and nursing facilities was attributable to nursing facilities. Community residential services spending for persons with physical disabilities grew an average of four percent per year on an adjusted basis from 1997 to 2006. Institutional spending for nursing facilities for this population was essentially static, advancing only 0.4 percent per year between 1998 and 2001 and then declining 1.4 percent per year between 2002 and 2006.

Consolidated inflation-adjusted long-term care spending for persons with mental and physical disabilities in institutions and nursing facilities increased only 0.2 percent per year from 1997 to 2006. However, community services spending grew rapidly, at 5 percent per year. Total consolidated inflation-

adjusted community services spending for disability services surpassed institutional spending in 2005. In summary, services and funding for persons with disabilities are gradually moving toward smaller, more individualized community settings. Consequently disability-related community development finance opportunities are poised to continue growing comparatively rapidly in the future.

Market Opportunities

Spending on disability-related services and income maintenance is growing. As a percentage of all federal, state, and local governmental expenditures, total disability spending advanced by 12.4 percent from 1997 to 2006 (Office of Management and Budget, 2009). However, institutional and nursing home long-term care spending increased by only an inflation-adjusted two percent, and the number of recipients in institutional settings actually decreased by nine percent. In contrast, community-based long-term care spending advanced 52 percent during 1997 to 2006, and the number of participants in these settings increased 31 percent. Community services growth is strongest in the I/DD field, while nursing facility care continues to be extensively utilized for people with physical disabilities and mental illness. However, the use of community and family support-based settings for physical disability and mental health care is poised to increase as these community support models become increasingly emphasized in legislation and through the courts (Sulzberger, 2010).

Long waiting lists for community residential services are commonplace today, and access remains a significant problem in many parts of the country for people with mental and physical disabilities (Kaiser Commission on Medicaid and the Uninsured, 2008a; Prouty, Smith, and Lakin, 2007). Many people with disabilities are currently living with aging caregivers who themselves require, or will soon require, community residential support services. In the absence of an adequate supply of such services, the caregiver and those cared for are both at risk of being inappropriately placed in nursing facilities.

One emerging innovation addressing the community support needs of people with I/DD and aging populations is “smart home” technology. The technology has the potential to improve service quality, reduce staff turnover, and possibly cut staffing costs. Staff turnover in I/DD out-of-home residential care settings is typically very high, often above 50 percent per year (Mitchell and Braddock, 1994).

Residential support technology can help consumers live safely in community residential settings or in their own homes. Smart home technology includes: 1) motion, temperature, door break, and carbon monoxide sensors and floor pressure pads; 2) personal emergency response systems; 3) personal digital assistants customized to facilitate activities of daily living; 4) selective access to appliances; 5) security and safety systems; and 6) web-based care information systems.

Medicaid financial support could be critical to national adoption of technology supports in residential care. Smart home technology has already received support from the state Medicaid program in Indiana, and Minnesota, Ohio, and West Virginia are considering Medicaid participation. For additional information on the use of smart home technology for I/DD see Imagine (2008), Rest Assured (2008), and Responsive Solutions, Inc. (2008); in aging, see Elite Care (2002) and Health Sense (2010).

The cognitive disability market for residential services and technology support is sizeable. More than 21

million people in the United States currently have a significant cognitive disability, which includes I/DD, severe and persistent mental illness, brain injury, and Alzheimer's disease (Rizzolo and Braddock, 2008). Careful evaluation of smart home technology and demonstration programs are required prior to widespread adoption of this innovation in service provision. However, residential support technologies carefully tailored to the needs of individual consumers with disabilities have the potential to enhance consumer self-direction, promote healthy lifestyles, and increase social interaction.

Current financing models for disability-related community residential services are underdeveloped and require integrating fragmented funding from federal, state, local, and private-sector sources. The community development finance sector may be able to help develop a more systematized and efficient funding system by providing start-up and patient capital, carrying some of the financial risk, developing financing models, and evaluating process and consumer outcomes. To develop viable models, the community development finance field will need to establish new partnerships with disability services organizations and improve its understanding of available federal, state, and local funding for support services required by people with disabilities. Community development finance organizations have a growing and potentially key role to play in helping our nation meet the growing demand for affordable, accessible, community-based housing for people with disabilities.

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Technical Note on Data Sources

General Health Care

Medicaid data were obtained primarily from the Centers for Medicare and Medicaid Services (2009) and the Kaiser Commission on Medicaid and the Uninsured (2007a); for Medicare, from the Centers for Medicare and Medicaid Services (2008), and for veterans' health care services spending, from the U.S. Department of Veterans Affairs (2007) and S.V. Panangala (2008).

Income Maintenance

Social Security Disability Insurance (DI) data were obtained from the Social Security Administration (2007a); Supplemental Security Income (SSI) data were obtained from the Social Security Administration (2006b); data for Adult Disabled Child benefits under Title II of the Social Security Act were obtained from the Social Security Administration (2006a); and SSI state supplement data were obtained from the Social Security Administration (2007b). Sources for veterans' compensation included the U.S. Department of Veterans Affairs (2007); sources for food stamp data included Barrett (2006) and

Wolkwitz (2007); and HUD rental subsidies were estimated based on data from the U.S. Department of Housing and Urban Development (2004).

Long-term Care

State-by-state data for I/DD long-term care services provided by state agencies were obtained from Braddock, Hemp, and Rizzolo (2008) and for mental health long-term care services provided by state agencies, the National Association of State Mental Health Program Directors (2009) and the Substance Abuse and Mental Health Services Administration (2009). Nursing facility data were obtained from the Centers for Medicare and Medicaid Services (Office of the Actuary, 2007) and the American Health Care Association (2009).

Data on other components of long-term care in the states came from Heinsohn (2009a, 2009b), Eiken and Burwell (2008, 2007), and the Kaiser Commission on Medicaid and the Uninsured (2007b, 2008). Data on other community-based Medicaid programs including personal assistance, health care, and targeted case management were obtained from Burwell, Sredl, and Eiken (2007) and the Kaiser Commission on Medicaid and the Uninsured (2009). Data on construction funding come from the U.S. Department of Housing and Urban Development (2007). Data on vocational rehabilitation services were obtained from the U.S. Department of Education, Rehabilitation Services Administration (2009).

Special Education

Regular education per pupil cost data by state were obtained from the U.S. Census Bureau for years 2000 through 2008 (2008) and from Zhou and Johnson (2008). Nationwide excess special-education cost factors were obtained from Chambers, Parrish, Lieberman, and Wolman (1998) and from Chambers, Parrish, and Harr (2002). Federal Individuals with Disabilities Education Act (IDEA) funding consisted of Part B, Section 611 (93 percent of federal special education funding to the states); Part B, Pre-school, Section 619 (3 percent); and Part C early intervention funding (4 percent) (U.S. Department of Education, 2009). The source of state government spending for special education was the U.S. Census Bureau for years 2000 through 2008 (2008) and a direct survey of 15 states' special education departments that did not report data to the Census Bureau. Local government special education spending in each state was estimated based on total special education spending less federal and state government special education spending.

We used an "excess costs" approach to estimate special education spending nationally and in individual states. Total excess special education cost *above* general education costs per pupil was \$8,186 nationally for the academic year 1999 to 2000, the latest year for which data were available (Chambers, Shkolnik, and Perez, 2003). Projecting these costs forward and adjusting for inflation, special education excess costs per pupil were estimated to be \$11,987 in 2006. The intervening years' costs were also estimated using this methodology.

The excess cost per pupil for students with emotional disturbance in 2006 was \$13,934; for I/DD (mental retardation, autism, traumatic brain injury, and developmental delay), \$14,970; and for physical/learning disability, the excess cost was \$11,088 per pupil. All other disabilities were included in a broad physical/learning disability category, which included multiple disabilities; hearing, orthopedic, visual, other health impairments; deaf-blindness; and general learning disabilities. We used the excess per pupil costs for each disability category to estimate total public special education spending at the federal, state, and local level.

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